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April 22, 2016

**Crystal Wren
SSPS III
HCBS Waiver
Long Term Services and Supports
DHCFP**

Dear Ms. Wren:

Here is our position paper / some questions that would more accurately define the types of patients in our facilities and their needs.

We believe that Olmstead (a ruling that requires states to eliminate unnecessary segregation of persons with disabilities and to ensure that persons with disabilities receive services in the most integrated setting appropriate to their needs) was looking at this group of people, the group with disabilities who are in an institution and might move to a less monitored but still very monitored safe home and community based care setting safety and cost effectively.

We also believe that instead of privacy and locked doors residents who need protective supervision and Long Term Care need companionship, and open doors so staff can get in easily in a case of emergency. These people want companionship and want to avoid isolation in a private room when they lack social skills to come out and interact with other people. We believe they need assistance with medications and need 24 -hr staff at some level so they can get a PRN medication when needed. If they can hold their own medication and can be trusted to take them we would argue they are less Long Term Care residents. If they are monitored by a pill count on a daily visit is that adequate monitoring to ensure a mentally ill person is putting that pill in their mouth even if it is not in the box the next morning? For all the choice questions while that sounds good in fact congregate care and living is about cost effective care to allow the 24 hour protective supervision they need. If money was unlimited then we all can choose our own home, feed, roommates but this is about cost effective care and choices that offer needed safety, protection and care. Already Residential Facilities for Group principles of care are patient centered from their creation of home like, non-medical care, that offers dignity, respect, independence, function, and safety in the least restrictive way. All of that with the required monitoring and safety and enforcement to ensure the Long Term Care residents needs are met. If they did not need monitoring and supervision they would not be Long Term Care residents. People don't go to Skilled Nursing Facility if they don't have to and what we are looking for is cost effective, home and community based care for those who need Skilled Nursing Facilities or high level of care for chronic illnesses that are unlikely to improve, have already plateaued with treatment.



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Instead of asking about job potential and privacy we need to ask about.

Answer all with do any of the residents meet this criteria? y/n Then how many out of the total are Long Term Care residents instead of independent / transitional living residents. For example, 8/10 if you have 10 beds.

-Do you have residents over age 60 who are less likely to seek work.? If so how many out of the total number of residents, you have?

-What is the average age of your resident?

-What is the average ADL level of your residents? Total independent, need some help, need a lot of help.

-Do they wear briefs or depends y/n

-Number that use a walker or adaptive device or don't walk at all?

-Do any of the residents have chronic mental, cognitive or other physical illness that limit their practically ever living alone or getting a job?

-Would getting a job or living on their own without 24-hour supervision put the safety of that resident at risk?

-List some of the diagnosis that your population suffers from that limit their ability to work, live alone?

-How many of your residents have already received therapy for their illness and still can't live alone or seek employment?

-Would locking the door to the room put your residents at risk in case of a fire or in case their mood changed quickly and needed assistance by the supervising person?

-Would taking your resident out in the community potentially agitate them and stress them cognitively or physically?

-Would leaving your resident alone in a room or at home without some level of monitoring put them at risk of bad events?

-Is there any scenario you can envision medically where your residents will with treatment medical or behavioral be able to live alone, work or live without protective supervision?

-If you had to average or guess would you describe your residents as independent living / transitional living or tending more toward Long term care residents who are closer to needing a nursing home than living on their own even with assistance, training and improvement in their health condition?

-What type of irreversible illnesses do your resident typically have?



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-Given the age and expected progression of needs for your residents is it likely any will improve enough to where they can be independent even with community supportive services?

-Would you agree that your residents might not get the needed supervision, protective supervision, and care they need if they get care in an independent living / transitional living setting where they have less than 24 hour care and a place that can give prn medications 24 hours a day when needed?

-Does your care setting offer coordination of medications?

-Does your staff ensure the residents take their medication? If so do they do it on an ongoing basis or through a one visit a day pill count? If it is by a pill count once a day how do you ensure the resident took the pills?

-If the doctor called in a medication change does the resident process that including drop the prescription off and pick it up from the pharmacy and record it?

-If not do you have staff to do this for the resident?

As discussed, we believe that this information will help us get the data we need to open up the discussion with CMS so that we can protect the Long Term Care residents we serve some of whom may be mislabel as transitional living / independent living and exposed to care setting with less monitoring and supervision than they need.

While it is a good idea to consider lumping all residents into one group in fact doing so by definition means one groups needs' will not be addressed. The more independent who need privacy, jobs, and job training are very different from those needing long term care, many of whom have chronic mental, cognitive or combinations of mental and physical disabilities that need companion ship more than privacy, supervision for safety and care more than independence and who can be upset by false hope of working again when that is not practical. We need to comply with CMS or better yet to help educate CMS with our data and response to these questions to help protect the disabled and to build / improve upon programs like the Residential Facilities for Group industry in Nevada that is a national leader in Olmstead compliant, community based, safe, monitored, cost effective care.

With the data and responses from Residential Facilities for Group (big and small) to a fair set of questions like the ones above we think we can apply for a grant to expand and build upon our national leading regulations that protect and empower seniors who have Long term care needs to help them SAFELY remain in the residential communities where they are used to live in spite of their disabilities and to help keep them out of institutions. Indeed, we believe Residential Facilities for Group in Nevada are already



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Olmstead compliant in this effort and already offer patient centered care, safety, but with monitoring and enforcement that is needed to ensure these disabled people get the care they need when they are unable to protect themselves.

We are hopeful that we can work with you and the strategic plan at expanding and modifying the next question list including building in a purpose for those questions to support our state plan and response to CMS. As you know lumping people into one group as CMS is requesting is coming under a lot of concern. Indeed, we can envision reaching out to other groups, senior research groups in Nevada to help as well to add credibility and help fund the next questionnaire. If we are working together with AHONN in the North, RCHCAN / ECHO in the South and NvAlc it is likely we can get a very high response rate to the next questionnaire.

We can be the leaders in suggesting cost effective changes that allow and promote those who need and benefit from it and building in a real cost effective, home and community based care option for those who are Long Term Care residents. We have many ideas on ways to have cost effective care that can grow that also promotes individual self-determination and responsibility. The good news is Nevada is already a leader in cost effective, Olmstead compliant, home and community based care in Residential Facilities for Groups under NRS 449.

We would like to work with you to help build the two systems to help the two very different groups of people independent living / transitional living and Long Term Care residents which we believe are the target group Olmstead is looking at. So far the questions and plan missed to see the safe, cost-effective care that the state can hope to fund as the number and demand for Long Term Care service increases. Paying 6K / resident / month for low acuity independent / transitional living residents is not cost effective but we believe there are many very safe, cost effective plan possible.

The regulations we are expected to follow right now from the BHCQC is mostly opposite of what CMS is asking the group homes to do. First and foremost, we would humbly suggest that the Department of Health and Human Services align these regulations with the requirements of BHCQC so that everyone is on the same page. It should be very clear that our recipients do not fall in the category CMS is talking about. Plain and simple, our residents are all long term care.

We hope we can work with you and the department concern to explore ways the state can offer choices in care, promote patient / family self-determination, and build in monitoring that helps reduce cost while allowing choice.

Sincerely,

AHONN Executive Board

c.c:

*Marta Jensen - Acting Administrator, Department of Health and Services
Jane Gruner – Administrator, Aging and Disability Services Division
ECHO
RCHCAN*